

Elk Grove Unified School District

WORLD RARE DISEASE DAY

Resolution No. 43

WHEREAS, *World Rare Disease Day is a one-of-its-kind international advocacy day to raise awareness of rare diseases; and*

WHEREAS, *World Rare Disease Day was established because treatment for rare diseases is insufficient as are the social networks to support individuals with rare diseases and their families; and*

WHEREAS, *Rare disease is a disorder in the USA when it affects fewer than 200,000 Americans at any given time; and*

WHEREAS, *80% of rare diseases have identified genetic origins and 50% of rare disease touch children; and*

WHEREAS, *over 6,000 rare diseases are characterized by a broad diversity of disorders and symptoms that vary from disease to disease and individual to individual suffering from the same disease; and*

WHEREAS, *as there are often no existing effective cures which leads to the high level of pain and suffering endured by the individuals and their families; and*

WHEREAS, *the lack of scientific knowledge and quality information on the disease often results in delay in diagnosis which often leads to heavy social and financial burdens on individuals; and*

WHEREAS, *the ongoing implementation of a better comprehensive approach to rare diseases has led to the development of appropriate public health policies along with international cooperation in the field's education, clinical and scientific research, as well as the sharing of scientific knowledge about all rare diseases; and*

WHEREAS, *World Rare Disease Day is observed on the last day of February*

BE IT FURTHER RESOLVED *that the Elk Grove Unified School District Board of Education does hereby recognize and proclaim February 28, 2015 as World Rare Disease Day.*